Building the PHDSC Web-based Resource Center

By

The Web-based Resource Center Work Group

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Building the PHDSC Web-based Resource Center
Executive Summary

Creation of the Web-based Resource Center Work Group
The Public Health Data Standards Consortium (PHDSC) Web-based Resource Center Work Group (WRC WG) was created primarily to design a Web-based Resource Center (WRC) that would aid public health practitioners and health researchers in becoming more aware of health data standards, encourage participation in the development of health data standards, facilitate implementation of health data standards, and help in stakeholder understanding of the fine points of the Health Insurance Portability and Accountability Act Administrative Simplification (HIPAA AS) provisions. The WRC through its efforts hopes to meet many of the needs identified in the Consortium Education Strategy report developed by the Lewin Group and The National Association of Health Data Organizations (in conjunction with the Consortium's Education Work Group). Several of the WRC WG members were also members of the Education Work Group, which has helped to maintain momentum and focus.

PHDSC Health Data Standards Survey
Members of the WRC WG developed and implemented the PHDSC Health Data Standards Survey (see Appendices) to supplement the PHDSC research for the Education Strategy report and to further determine the educational needs of public health data users related to the Health Insurance Portability and Accountability Act (HIPAA) and other data standards issues.

Highlights of the survey results based on 165 completed surveys are as follows:

Nearly a third of responders (29%) were from Local Health Departments. The next strongly represented group was State Health Departments at 20%. The rest of the choices listed in the survey for this question included Academic Institutions (8%), Federal Agencies (7%), For-Profit Organizations (7%), and Associations (3%), and Other (27%).

The "Other" agency/organization type was comprised of governmental health related services (19%), hospitals (19%), clinics or group practice (16%) other non-profit research, advocacy, and health services organizations (46%).

The collectors reigned as the lead stakeholder response group at 32%, with the users not far behind at 30%. Responders likely crossed the lines of stakeholder definition in their day-to-day work, but identified the definition with the best fit. Decision makers (16%), other (12%) suppliers (10%), and 1 funder (1%) completed the group.

A third of responders were not familiar at all with HIPAA AS.

Familiarity with the basic process of health data standards development at the national level was non-existent for just over a third of the respondents to the PHDSC survey (35%).

A substantial number of responders have not participated in standards development at the local level (58%), at the state level (63%), and at the national level (75%).

More than two-thirds of respondents declared that either there was a process in place for developing health data standards at their agency or organization or that a process was planned.

For the question that asked responders to choose all of the listed agencies/organizations that their agency/organization shares health data with (neither public or private health care providers defined), the three human hospital options were at the top and received similar rankings at 56% of responding agencies/organizations for inpatient, 50% for emergency departments, and 49% for outpatient. Following are two other types that are closely related; home health at 33% and nursing homes at 32%.

85% percent of responding agencies/organizations engaged in data sharing.

Responding agencies/organizations shared with the private (62%) and public (79%) sectors.

The top two private sector entities that health data were shared with were physicians/medical providers (14%) and insurance carriers (10%).

Half of responders relied on at least one organization or agency for early warning/emerging health threat information. Of these responders, 20 identified hospital emergency departments, 17 said hospitals (not laboratories or emergency departments specifically), 15 indicated state health agencies (not laboratories specifically), and 10 listed laboratories. Hospitals (public and private) apparently serve as a major resource for outbreak information.

18 identified at least one private sector entity as one they received early warning/emerging health threat information from. Four listed hospitals (without a department specified), three wrote hospitals (emergency department) two declared hospitals (infection control department), three indicated insurance companies, and two stated EMS Providers.

22 identified at least one public sector entity as one they received early warning/emerging health threat information from. Seven listed local health departments, five indicated EMS agencies at differing jurisdictional levels, and five also listed the state health department.

The major health data transactions (data exchanges) agencies and organizations are concerned with are notifiable diseases (63%), encounter (61%), and laboratory (48%).

The top five health data code sets identified as being used by agencies and organizations were ICD-9-CM for diagnoses (72%), CPT-4 (45%), ICD-9-CM, Vol. 3 for procedures (41%), ICD-10 for cause-of-death data (33%) and HCPCS (22%). NDC weighed in at 7% and SNOMED at 6%.

The leader in message format standards for agencies and organizations, according to survey responders, is Health Level Seven (HL-7) at 21%. X-12 (8%) and NCPDP (6%) were close in popularity.

The primary barriers to implementing health data standards in responder agencies and organizations included: economic issues (at 14% of responders), variable capacity or readiness of data users/systems internally (11%), time requirements (9%), and technical issues (9%). All 15 of the barriers that were listed received at least 3 votes.

When asked if they were aware of where to locate national health standards of interest, 33% of survey responders said no.

Of eight training methods proposed in the survey, responders embraced computer-based training (on-line self-paced tutorial) as the training format most useful to health data staff at their agency or organization (22% of responders).

The primary barriers that prevent health data staff at agencies and organizations from obtaining up-to-date health data standards training, according to the survey responders, include: scheduling/time issues (46%), lack awareness of relevant training (45%), economic issues (42%), and differing staff capabilities (28%).

Most responders (69%) indicated that both general training (overview of health data standards) and specific training (focused on specific standards) would be the preferred web-based training approach for health data staff in their agencies and organizations.

More than half (56%) of responding agencies and organizations, based on survey results, do not provide health data standards training to staff.

42% of responder health data offices have the ability to receive Webcasts for more than 75% of their staff.

54% of responder health data offices have access to PowerPoint for more than 75% of their staff.

Design, Development, and Management of the WRC
The WRC WG members are focused on making it easy for health researchers and public health practitioners to learn about health data standards, to exchange ideas, to promote health data standards within their own organizations as well as among organizations they share data with and at other jurisdictional levels.

Efforts are underway to design a user-friendly Web-site to make the aforementioned goals possible. The projects being worked on in the Consortium, responses from the survey, and suggestions by public health leaders, practitioners, and researchers will help determine content.

The members of the WRC WG have already developed a list of annotated Web-sites, focusing on categories and Web-based content that they believe will be useful for visitors to learn about HIPAA and other data standards issues.

Suggestions for WRC promotion include: listservs, direct mail, newsletters, journal articles, speaking at events, a compendium of PHDSC meeting proceedings, and **assistance from Consortium members in marketing the WRC on their Web-sites.**

As the WRC grows, a second generation site is envisioned, with personal customization and advanced methods of stakeholder interaction as the primary new features.

The WRC WG suggests the hiring of a capable contract staff and governance by a Board of five to ten representatives from the PHDSC Steering Committee.

The Public Health Community's Availability of Health Data Standards Information

The Public Health Data Standards Consortium serves as a forum for organizations with a public health focus and an interest in national data standards. Only through better information can the Consortium seek and achieve its mission to improve the health and healthcare of the nation's population. The use of information technology is a valuable means to this end with the mission being accomplished by improving the exchange of healthcare data and standardizing the data content and its electronic format between healthcare stakeholders.

A 2001 study conducted by The Lewin Group and the National Association of Health Data Organizations (NAHDO) identified three models within the public health community representing current efforts for national standards development and implementation. Three such efforts include the North American Association of Central Cancer Registries (NAACCR), the Committee for Immunization Registry Standards and Electronic Transactions (CIRCET) Workgroup, and the national Vital Statistics systems specific to birth certificate activities. Although these three models embrace a national consensus process necessary to develop national standards, the participants in the activities continue to face the challenges of financial, political and cultural barriers to local implementation.

The challenges the public health community faces in order to succeed in adopting national standards are numerous and the barriers are significant. The Lewin Group and NAHDO study identified some of the challenges in adopting standards specific to public health. One major challenge includes overcoming the existence of the many independently developed information systems, which are known in the healthcare industry as categorical or proprietary systems. For example, many existing public health information systems were designed to meet the public health agency's local needs with a regulatory mandate based on the jurisdiction of the agency. Changing these information systems in place today by incorporating a national standard will prove costly and possibly disruptive to the day-to-day operations.

Even with these financial and operational cost barriers, the benefits of migrating to national standards give the public health community a greater opportunity to transform their fundamental practice. With the recent terrorism events of September and October 2001, public health's monitoring responsibilities will be critical to the nation in preventing or responding to bioterrorism attacks today and in the future. Unfortunately, today's public health systems are either inadequate or nonexistent for collecting data about chemical and biological terrorism (Yasnof et al, 2000). This is one reason that stakeholders in the business of providing healthcare and consequently collecting health data are discussing new and

innovative ways to communicate formerly not seen, imagined or thought possible before this tragic event.

To leverage the events of 9.11, another national standard development activity may prove beneficial to public health and the nation as a whole. This activity is called the implementation of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (P.L. 104-191).   Originally this law was passed by Congress to reform the health insurance industry and to simplify healthcare financial and administrative processes. With 26 cents of each healthcare dollar being spent on overhead costs, the implementation of the HIPAA Administrative Simplification provisions will significantly reduce the healthcare industry's administrative burden. This will be accomplished by using a national standard for electronic data interchange (computer-to-computer communication) for healthcare transactions and using uniform data elements and code sets. Other relevant areas to public health as covered under HIPAA include the use of standard identifiers for healthcare providers, health plans, employers, and individuals (patients); security standards required at all stages of transmission and storage of healthcare information ensuring the integrity and confidentiality of the health; and privacy standards defining what are appropriate and inappropriate disclosures of individually identifiable health information and how patients' rights are to be protected (WEDI SNIP, 2002).

Although public health agencies are not mandated to comply with HIPAA, many are adopting policies consistent with HIPAA's intent, recognizing the added value for public health capabilities. It is difficult to ignore the healthcare industry standards when information systems such as hospital discharge databases, disease registries (e.g., tumor registries, reportable disease databases), trauma registries, vital statistics, and immunization registries that are public health surveillance databases, rely on healthcare encounters to trigger data reporting. Clearly the pressure to conform to HIPAA standards will be evident within the healthcare industry in the coming months when covered entities must meet the compliance deadlines.

While HIPAA targets benefits specifically within the business of healthcare, the Consortium's support for the public health community to leverage HIPAA standards can go to the heart of healthcare: to improve the health and healthcare of the public. Many of the Consortium members are indirect stakeholders in the HIPAA law.   A 2000 study conducted by NAHDO explored the value of discharge data systems to the public health community and identified forty states collecting inpatient discharge data. The collection of this data allows for health services researchers to analyze the data while assessing the quality of patient care (Elixhauser, 1998). Two measures in quality care tracked through administrative data sets include the evaluation of preventative care and of sentinel events – those that should not occur in any circumstance. Although Elixhauser recognizes the shortcomings of administrative data (lacking clinical detail) she also sees national data standards profoundly impacting the quality of

data. This would be accomplished by reducing the variability of data systems, data elements, and code sets thus facilitating comparisons across healthcare agencies within and across states.

After September eleventh, it will be much less difficult to convince health policy decision makers the value of health data collection across the nation, within the States, and through the many public and private healthcare operations. To succeed at the mission of improving the health and healthcare of the public, the Consortium is currently identifying the significant stakeholders in the standards arena and attempting to build a strong constituency through partnerships with these stakeholders. The Lewin Group (2001) identified an educational strategy, which lists the major categories of healthcare stakeholders as decisions makers, funders of standards within the healthcare process, and the collectors, users, and suppliers of data. Within the educational strategy Lewin recommended the need for the Consortium members to participate in and support the process of standards development through the development of a web-based resource center. As a result of this recommendation, a workgroup, called the Web-based Resource Center Work Group (WRC WG), formed in the Summer of 2001 with the intent of conceptualizing and creating a plan for an Internet website for its members that would help them get the health standards information that they need.

Using the educational strategy as an initial guide for this activity, the workgroup relied on the barriers and strategies identified in the Lewin report (2001). The strategy report named three major stages for the Consortium to follow when working to achieve their objectives: build partnerships and educate constituencies, participate in standards development; and support standards implementation. The latter two stages incorporate the need for the public health community to develop and implement a web-based resource center. Additionally, the study found several issues specific to public health that need to be addressed at a policy or legislative level: lack of a unified national leadership in the standards development process; lack of funding for these efforts; and lack of uniformity in how public health is structured. Other issues, again specific to public health and at a more practical or hands-on level include: lack of knowledge in knowing where and how to participate in the standards process; lack of coordination across multiple data standardization and integration efforts; and lack of necessary staff knowledge and skills to combine information technology and public health practices. These issues are not unique to the healthcare industry and the HIPAA process is an example. The private sector has formed partnerships with the necessary stakeholders to overcome these same barriers. A resulting web-based resource center such as the one developed by WEDI SNIP could serve as a model for the public health community.

Although all of the above mentioned issues create a challenge for the Consortium and the WRC WG, the Lewin study confirmed a clear need for a public health resource center dealing with national health data standardization.

To gain further understanding of the resource needs within the public health community, the WRC WG, with assistance from the Public Health Foundation, a Consortium member, conducted a survey to obtain feedback from the public health and health services research communities on the need for educational material about health data standards (see appendices). The workgroup intends to use the survey results to provide guidance in the development of a Web-based Resource Center used for tracking health data standards development efforts. Other activities performed by the workgroup included developing and posting an inventory of existing web-based resources divided by topic category that provide education and information about health data standardization issues (see appendices). Further areas to be explored by the workgroup in the development of the resource center include the possible use of portal technology, which could include search engines, bulletin boards, listservs, and centralized training tools such as computer-based training (CBT) modules.

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Overview of the PHDSC Health Data Standards Survey and Implications for the Web-based Resource Center

WRC WG Purpose
The Public Health Data Standards Consortium (PHDSC) Web-based Resource Center Work Group (WRC WG) was created primarily to design a Web-based Resource Center (WRC) that would aid public health practitioners and health researchers in becoming more aware of health data standards, encourage participation in the development of health data standards, facilitate implementation of health data standards, and help in stakeholder understanding the fine points of the Health Insurance Portability and Accountability Act Administrative Simplification (HIPAA AS) provisions.

Survey Development and Promotion
Members of the WRC developed 29 questions for the PHDSC Health Data Standards Survey (see Appendices). It was posted to a WRC WG members private Web-site and promoted via Web-site postings at health organizations and via messages and newsletters sent by members of these organizations to their colleagues and constituents.

The survey was accessible for on-line responses December 14, 2001 through January 31, 2002. 165 responses were recorded. The Work Group would have preferred to have a greater number of responses to increase the validity of the results, especially since the 165 responses was also broken down to smaller subsets to highlight specific groups throughout this paper. The sampling was not scientific because of time and other resource limitations, but the WRC WG feels that the responding organizations and stakeholders were representative of the PHDSC constituency. The survey marketing style was broadcast instead of focussed on a specific type of stakeholder. There was an interest in determining broad-based needs and capacities. Members of the analysis team believe that the results are representative of what they have experienced in the field or been advised of by their colleagues.

Survey Adjustments
Some responses for specific questions were discounted due to a change in two questions (Q. 12 and Q. 22) after four responses were already received, and when narrative or numerical responses indicated a clear misinterpretation of the question. The respective questions are identified in the full survey results, by changes in the "N" count. A few responses for Q. 23 indicated both "Yes and No." Due to programming error the template did not force one or the other answer as intended. Such answers were counted as "Yes" since the analysis team considered that any amount of training should be considered as "Yes."

Additional Analysis Planned
The Work Group considers the analysis presented in this paper to be a partial snapshot of the needs of the responders. Further analysis will continue, as time

allows, utilizing additional crosswalks to gain further insight into the data. The Work Group welcomes continued feedback on the published survey results and the sentiments and thoughts of academicians, health researchers, and public health practitioners on Web-based health data standards training in general. Please visit www.cdc.gov/nchs/otheract/phdsc/contacts.htm for contact information.

The WRC WG considers that the survey results may also be useful in helping to identify future health data standards development needs, based on responses to narrative questions and may serve as a catalyst for future brief surveys, that will focus on limited issues.

Survey Results and Implications for the WRC
Nearly a third of responders (29%) were from Local Health Departments. The next strongly represented group was State Health Departments at 20%. The rest of the choices listed in the survey for this question included Academic Institutions (8%), Federal Agencies (7%), For-Profit Organizations (7%), and Associations (3%), and Other (27%).

The "Other" agency/organization type was comprised of governmental health related services (19%), hospitals (19%), clinics or group practice (16%) and other non-profit research, advocacy, and health services organizations (46%).

The collectors reigned as the lead stakeholder response group at 32%, with the users not far behind at 30%. Responders likely crossed the lines of stakeholder definition in their day-to-day work, but identified the definition with the best fit. Decision makers (16%), other (12%) suppliers (10%), and 1 funder (1%) completed the group.

A third of responders were not familiar at all with HIPAA AS. It may not have been a requirement for their division and possibly even their agency. However, knowledge of HIPAA AS provisions and practice of the same will go a long way in helping health departments and other health agencies/organizations share data and work on related areas with those who do. The purpose of this paper is not to discuss all the reasons why HIPAA AS and health data standards training is of great importance, although points will be made throughout that support this view. The Education Strategy report already provides a sound, researched, detailed, and supported case.

Familiarity with the basic process of health data standards development at the national level was non-existent for just over a third of the respondents to the PHDSC survey (35%). Such standards impact all health agencies and would benefit from some form of representation from all stakeholders. The WRC would be right in its mission to strive to lower this percentage through fact sheets, tutorials, and information on historical development steps.

A substantial number of responders have not participated in standards development (58% at the local level, 63% at the state level, and 75% at the national level). Those that did respond are the type of people that may likely know what measures are most useful. Many of these people have served at different jurisdictional levels throughout their career. All jurisdictional levels of development would benefit from viewpoints at all levels. The WRC can help to increase participation through the posting of materials and tools that educate on the topic of health data standards development and help people at all jurisdictional levels participate at all jurisdictional levels.

Regarding intra-organizational standards, the picture was rosier. More than two-thirds of respondents declared that either there was a process in place for developing health data standards at their agency or organization or that a process was planned.

One of the questions on data sharing ("Does your agency/organization share data with health care providers?") was somewhat vague and the WRC WG received some complaints in this regard within the comment section of the survey. Survey designers felt that the question could be presented in countless ways with varying degrees of specificity. For this question they wanted to establish the amount of general sharing taking place. 85% percent answered yes.

According to the survey results for the question that asked responders to choose all of the listed agencies/organizations that their agency/organization shares health data with (neither public or private health care providers defined), the three human hospital options were at the top and received similar rankings at 56% of responding agencies/organizations for inpatient, 50% for emergency departments, and 49% for outpatient. Following are two other types that are closely related; home health at 33% and nursing homes at 32%. Although not a listed option, physicians, other medical providers, and "doctors' offices" were identified by 31 responders (19%). Veterinary clinics and hospitals registered 15%, but may increase in prominence with the increased threat of terrorism for our nation. Public health agencies were specifically identified by 14 responders (8%) as other health care providers that data were shared with. Had this been a listed option, the percentage may have been higher.

Respondents were asked about agency/organization sharing with the private and public sectors. Significant sharing was occurring for both, with the public sector

at 79% and the private sector at 62%. Since more than half (59%) of the respondents were from governmental health and medical agencies, it is not surprising that the public sector held the top position. Any sharing would benefit from standardization of terms, format, etc. However, the WRC WG acknowledges that some data sharing is done via aggregated data reports and some of the sharing is purely outbound.

The survey included narrative questions to help the WRC WG learn about the type of organizations that information was shared with. The top two private sector entities that health data were shared with were physicians/medical providers (14%) and insurance carriers (10%). 16% of responding agencies/organizations identified that they shared with state health agencies (one of the responders in this regard was from a state health department). 16% also identified that they shared with local health agencies (ten of the responders in this regard were staff from local health departments).

The survey asked if the responder relied on any health care providers for early warning/emerging health threat information, to list the type of agencies/ organizations and departments if appropriate. Half of them relied on at least one organization or agency for this type of information. Of these responders, 20 identified hospital emergency departments, 17 said hospitals (not laboratories or emergency departments specifically), 15 indicated state health agencies (not laboratories specifically), and 10 listed laboratories. Hospitals (public and private) apparently serve as a major resource for outbreaks information. Since many hospitals already have or are embracing HIPAA AS provisions, it would be in the interest of public health agencies to do the same so that they can share data more effectively. For-profit hospitals must respond to their investors and owners. If data coming from other health agencies is not in the same format as data they utilize, they will find little value in it or applicability to their client population.

95 of the responders that identified their agency/organization as one that shared data with the private sector indicated the private sector agency/organization type. Of this group, 18 identified at least one entity as one they received early warning/emerging health threat information from. Four listed hospitals (without a department specified), three wrote hospitals (emergency department) two declared hospitals (infection control department), three indicated insurance companies, and two stated EMS Providers as a source of early warning/emerging health threat information.

120 of the responders that identified their agency/organization as one that shared data with the public sector also indicated the type of public agency or organization. Of this group, 22 identified at least one entity as one they received early warning/emerging health threat information from. Seven listed local health departments, five indicated EMS agencies at differing jurisdictional levels, and

five also listed the state health department as a source of early warning/emerging health threat information.

As a result of the recent terrorism events, it is prudent to take preparedness seriously. As part of a comprehensive strategy, all the major agencies that share emerging health threat information, such as hospitals, emergency medical services providers, health departments, and insurance companies would likely benefit not only by planning response procedures together, but by also engaging in standardized electronic data sharing, and using standardized terms and symbols in shared printed reports. Seamless information sharing in between the public and private sector will help to provide the edge we need to protect our communities when time is a limited resource. 'A clock has arms, but standardized data has legs.'

The major health data transactions (data exchanges) agencies and organizations are concerned with are notifiable diseases (63% of responders), encounter (61%), and laboratory (48%). Vital records or statistics were mentioned by 3% and the same number also mentioned immunization data.

The top five health data code sets used by agencies and organizations were ICD-9-CM for diagnoses (72% of responders), CPT-4 (45%), ICD-9-CM, Vol. 3 for procedures (41%), ICD-10 for cause-of-death data (33%) and HCPCS (22%). NDC weighed in at 7% and SNOMED at 6%. However, in the narrative, two other responders mentioned SNOMED that had not checked the boxes for SNOMED (one of the responders was unsure of its use).

The leader in message format standards for agencies and organizations, according to survey responders, is Health Level Seven (HL-7) at 21%. X-12 (8%) and NCPDP (6%) were close in popularity. 38% of agencies or organizations that listed HL-7 also listed X-12; 10% of agencies or organizations that listed HL-7 also listed NCPDP. Agencies and organizations that listed HL-7 represented the following percentages of their agency/organization type: 33% of State Health Departments 31% of Academic Institutions, 27% of Federal Agencies, 19% of Local Health Departments, 16% of Other agencies/ organizations, 9% of For-Profit organizations, and no Associations listed HL-7 as a message format standard that is used.

Three medical doctors from the Regenstreif Institute for Health Care, that have researched electronic laboratory reporting, relate that their experiences have indicated the need for improved compliance with HL-7 by laboratory information systems (Overhage et al, 2001). Also as part of recommendations developed at the American Medical Informatics Association (AMIA) 2001 Spring Congress, attended by many PHDSC members, it was indicated that as part of improving public health reporting, development of HL-7 messages for notifiable diseases was important (Yasnof et al, 2001).

When asked if they were aware of where to locate national health standards of interest, 33% of survey responders said no. Making this information easily accessible is a must for the WRC.

The primary barrier to implementing health data standards in responder agencies and organizations varied greatly across the different agency types. The top reasons listed included: economic issues (at 14% of responders), variable capacity or readiness of data users/systems internally (11%), time requirements (9%), and technical issues (9%). All 15 of the barriers that were listed received at least 3 votes. This is an indication that there is a great need for research in addressing such barriers as well as a need for the WRC to make this research accessible.

The primary barriers that prevent health data staff at agencies and organizations from obtaining up-to-date health data standards training, according to the survey responders, include: scheduling/time issues (at 46% of responders), lack awareness of relevant training (45%), economic issues (42%), and differing staff capabilities (28%).

Most responders (69%) indicated that both general training (overview of health data standards) and specific training (focused on specific standards) would be the preferred web-based training approach for health data staff in their agencies and organizations.

Of eight training methods proposed in the survey, responders embraced computer-based training (on-line self-paced tutorial) as the training format most useful to health data staff at their agency or organization (22% of responders). This method would especially help to address the barriers of scheduling and differing staff capabilities.

More than half (56%) of responding agencies and organizations, based on survey results, do not provide health data standards training to staff. With money and time being top issues, as well as differing capabilities and stages of readiness, a centrally developed resource, accessible to all and free to all stakeholders makes sense. The economy of scale becomes a useful concept in this case. Rather than ask hundreds of agencies and organizations to put a combined figure of several million dollars into training development and implementation, the WRC could provide a more robust and "standardized" approach to health data standards training, and at a significantly lower cost. With a centralized focus of resources and brain-power, standards development and implementation can be put on the fast-track. It could serve as the neutral meeting ground where ideas are molded into life saving progress. The time-savings for countless health agencies and thousands of workers would enable a greater focus of practitioner hours on morbidity and mortality reduction.

The survey queried the computer capacities of the responder health data offices to aid the WRC WG in choosing training content delivery formats. 42% of responder health data offices have the ability to receive Webcasts for more than 75% of their staff. This number will likely grow as broadband services proliferate and costs are driven down. 54% of responder health data offices have access to PowerPoint for more than 75% of their staff. This information should encourage the Work Group to plan for on-line presentations in the respective formats. Greater discussion on this survey section is included later in the paper. Also included are a local and state views from authors that work at the respective jurisdictional levels.

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Stakeholder Familiarity with Health Data Standards
A Local Health Department View

General Survey Observations:

Forty-eight local health departments responded to the survey representing 29% of the total respondents. The LHDs described their stakeholder relationship as follows: 35 % consider themselves to be collectors of public health data, 31% decision-makers, and 23% percent users of public health data. Although the sample size is only a small percentage of the nations local health departments, the responses do offer some insights into how local stakeholders view their familiarity with health data standards. Over half of the LHD respondents were "not at all familiar" with the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act (HIPPA AS) and the rest were only "somewhat familiar" with HIPPA AS. Also, only 4 percent of LHD respondents were "very familiar" with the basic processes of health data standards at the national level while 43% were "not at all familiar" with these processes.

Specific Survey Observations:

Two of the questions related to personal participation in health standards development and indicate that LHD respondents have not been fully participating in standards development at either the local, state or national levels. As might be expected the level of participation drops off from 50% at the local level, to 36% at the state level, and only 26% at the national level. Interestingly, respondents were equally likely or unlikely to "often" (3%) participate in health standards development at both the state and national levels. From these responses it appears that health standards development at the state and national levels has very limited LHD involvement.

The majority of LHD respondents do not have a process in place for developing (66%) and adopting (56%) health data standards. Fortunately, 62% of respondents without processes for developing and adopting standards indicate that such processes are in the planning stages. These responses suggest that health standards development is just beginning in most LHDs while a small minority probably has not even begun to address the issue.

Sharing data with other health care providers and the public sector is common practice among LHD respondents (99% and 97% respectively). Most (67%) share health data with the private sector.

Only a small percentage (12%) of respondents is aware of where to locate national health data standards of interest to the particular LHD. Most (54%) of the respondents were only "somewhat aware" of where to locate national standards and 34% did not know where to look for national standards.

Little health data standards training is made available to LHD staff. Eighty-three percent of the respondents provide no training at all.

Survey Observations and Reflections:

In summary, the responses from LHDs participating in the survey indicate that these departments vary widely in their familiarity with health data standards. Most respondents have familiarity with HIPPA AS and other health standard development issues at the national level. However, few respondents are personally involved in issue development at either the state or national level and only a small number of respondents are aware of where to locate national health data standards. Although almost every respondent is engaged in sharing data with other health care providers and with the public sector, less than 25% of the respondents have a process in place for developing and adopting health data standards and very few provide health data standards training to staff.

It is important that LHDs become more involved in health standards development efforts at both the state and national levels and efforts should undertaken to increase local involvement. Perhaps, NACCHO could be instrumental in recommending LHD personnel to serve on state and federal level work groups. Also, it is apparent that LHDs have widely varying familiarity with health data standards indicating the need to improve both the medium and form of communications to the local level. Since almost all health data are first generated at the local level we must find ways to better familiarize our LHDs with data standards or the quality of the data will be compromised. Again, it would appear advisable to include LHD personnel in determining better ways to familiarize LHDs with health data standards.

Stakeholder Familiarity with Health Data Standards
A State View

General Survey Observations:

Though the survey did not have large numbers of responders, I believe from my conversations with other state data collection organizations that the results are representative. State Health Departments represented 20% of the responders on this survey. Taken as a whole, the survey paints a very encouraging picture about the standards awareness and the desire to develop systems using appropriate health data standards. The survey confirms that there is a wide spectrum of barriers that will create challenges to implement standard-based health data systems.

Specific Survey Observations:

Highlights:

- 66% of the responders are somewhat or very familiar with HIPAA
- 65% of the responders are somewhat or very familiar with the basic processes of health data standards development at the national level
- 69% of the responders reported a process to develop and adopt health data standards at their organization
- The responders indicated that data are shared with health care providers (85%) and with private sector users (62%)
- All responders reported using some kind of standard Health Data code set.
- 65% of the responders reported that they were aware of where to locate the appropriate national health data standards.
- The responders reported a wide range of barriers with no dominating response. The lack of funding was reported the most, but did not dominate the responses.

Survey Observations and Reflections:

Most survey responders reported that they shared data with some other entity. This is a significant finding in the survey, that I feel would surely be replicated if there had been a larger number of responders. Along with sharing data comes the responsibility of assuring that data are used appropriately by anyone given access. This survey finding is very consistent with dialog within my state as well as that at national meetings where data dissemination is discussed. The HIPAA privacy legislation is a core issue for covered and non-covered entities alike when discussing access to health data issues.

It is not surprising that all responders currently use a recognized health data code set. That result combined with the two-thirds majority of responders that are in the process of developing or adopting health data standards at their agency / organization is very encouraging for advocates of standards. It would be interesting to see if this result would be replicated with a larger sample size.

Even with a small sample size, the survey illustrates the barriers will make implementation of health data standards a challenge. The survey illustrates there are wide ranging issues with training from availability of relevant training to a lack of awareness about training needs. There are obvious economic barriers. I believe both of these observations from this survey would be replicated with a larger sample size. Though the barriers point out the some of the difficulties along the way, the bigger problem would be that the responders were unaware of the existence or value of health data standards. The survey is one indicator that this is not the case.

Conclusion about Stakeholder Familiarity with Health Data Standards

"People want to implement standard-based systems, but it won't be easy."

PHDSC Health Data Standards Survey
Detailed Analysis of Questions 22-28

Economic issues were identified as the primary barrier to implementing health data standards in agencies/organizations that responded to the Health Data Standards Survey. Variable capacity or readiness of data users/systems internally was another barrier that was identified as a close second to the economic issues. The following proposed barrier options were selected with almost equal distribution of responses: technical issues; time requirement; paper records as the primary method; variable capacity or readiness of data users/systems externally; training obstacles; and complexity of clinical data. Lack of chief executive officer/top executive buy-in; political complications; data integrity issues; privacy issues; belief that public health is exempt; security issues; and disbelief in value of standards were not identified as significant primary barriers by the majority of respondents.

Health data standards training within various agencies/organizations has been identified as a major issue that prevents the public health community from obtaining information related to health data standards issues. More than half of the respondents indicated that their agency/organization does not provide health data standards training to staff. Scheduling/time issues; lack of awareness of relevant training; and economic issues were the most significant barriers to obtaining up-to-date health data standards training. Respondents overwhelmingly agreed that there is a need for both general and specific web-based training in their facilities. The general training was described in the survey as an overview of health data standards while the specific training focused on specific standards.

The majority identified self-paced, on-line, computer-based tutorials as the most useful format to provide health data standards training. Others recognized conference/meeting; satellite-based conference; and computer-based training (off-line self-paced) as other useful training formats. Interestingly, one of the most common training mediums, videotaped lessons, was the least favored training format. The web-based resource center should meet the needs that were identified by the respondents by providing self-paced, on-line, computer-based tutorials.

The number of health data staff varied tremendously throughout the types of agencies/organizations. Fifty-eight percent of the respondents indicated that their agencies employed between one to twenty-five full-time and full-time equivalent health data staff. There was no consistency among the organizations between their ratio of health data staff and agency type. For instance, the range of health data staff within state agencies varied from two to five hundred. Sixty-three percent of Local Health Department respondents indicated that their agencies employed ten or less full-time and full-time equivalent health data staff. This creates an opportunity for the web-based resource center to increase public

awareness within state and local agencies regarding the need to employ health data staff. The health data staff should be cognizant of the issues surrounding health data standards and serve as the communication link to their organizations. In retrospect, it would have been useful to obtain information regarding the size of the various agencies/organizations to compare with the number of full-time and full-time equivalent health data staff.

Although respondents provided much feedback on the survey related to the health data standards issues, their responses to the web-based training capacity section was limited. Approximately forty percent of the respondents did not indicate whether they had access to a computer with a 56K modem or less. However, thirty-four percent indicated between 76 to 100 percent of their staff have access to a computer with a 56K modem. In order for organizations/ agencies to effectively access training materials from the web-based resource center, they must have adequate web-based training capacity.

Forty-two percent of the survey respondents stated that the majority of their staff have the ability to receive Web casts (streaming video). This is also true for forty-seven percent of State Health Departments. Overall, at least thirty-six percent of respondents have the ability to view satellite transmissions and listen to sound transmissions over the web. This provides an excellent opportunity for the web-based resource center to incorporate Web casts modules for health data standards training.

MS PowerPoint is a popular presentation software utilized within the business environment. Fifty-four percent of respondents stated that the majority of their health data staff have access to MS PowerPoint. This is a significant number that should influence the format utilized in posting presentation materials on the web-based resource center.

Generally, it has been difficult to analyze the results of the web-based training capacity of the organizations/agencies that responded to the survey due to insufficient responses. It would have been enlightening to obtain more feedback regarding the respondents web-based training capacity to provide a more accurate reflection of their environment.

Design, Development, and Management of the PHDSC Web-based Resource Center

WEB-SITE DESIGN

The Education Strategy Served as a Catalyst for Action
Public Health Data Standards Consortium Education Strategy (PHDSC 2001) envisioned that the Consortium would develop a user-friendly Web-based tool that provides a listing of health data standards development efforts with annotations, contact information, and links to additional information available on the Internet. A search utility was described that would enable a visitor to type in a key word for a data element or data set into a search engine and link to information such as: whether standards are under development, which agency or organization is involved in developing the standard, which standards setting organization has purview over this type of standard, the status of standard development, the implications of the standard for public health, contact information for persons involved in the standards development, links to experts via industry organizations, and other resources available on the Internet.

Persons interviewed during the assembly of the Educational Strategy suggested the development of Web-based fact sheets, guides, tutorials, etc. that would spell-out the main steps of the standards setting process in support of integrated data systems. They also had an interest in Web-based materials that would aid in locating appropriate funding and even grant application templates to speed and simplify the work.

The Education Strategy provided this early conceptualization of an easily accessible tool that would highlight activities by states, regions, and programs on standards implementation and data integration. This tool was recommended to have a sharing of knowledge, approaches, etc. among the public health and health services research communities.

The WRC WG determined that it was best to focus on health data standards (to include administrative data), before seriously highlighting its relationship to data integration projects. The suggestions made within the Educational Strategy for health data standards training and funding facilitation will be further analyzed and determinations made for the timing and manner of their use.

A User-friendly Approach
Plans are to initially use a text-based search function and/or Access database query system, possibly built upon an SQL system for speed. Functionality will be stressed, with 'looks' (imagery etc.) being secondary to navigation. As part of functionality, we will investigate basic methods of stakeholder information/tool submission, with a review process to assure quality postings. To aid with the use of search utilities and other tools, FAQs (frequently asked questions) that are

easy to reach and context sensitive, will likely be developed. To aid with navigation, metatags with keywords appropriate to likely searches to help direct people to the information will be applied. In addition, descriptors may be added (within navigational structures and near document headings) that help visitors understand the type of information and when the information is useful for specific roles, (e.g., collectors).

The Medicaid HIPAA Compliant Concept Model (MHCCM) at www.mhccm.org is a very image driven site that tastefully blends imagery and navigation. This site should serve as one of the most useful links and models to emulate.

To rephrase an earlier statement, we want to make it easy for health researchers and public health practitioners to learn about health data standards, to exchange ideas, to promote health data standards within their own organizations as well as among organizations they share data with and at other jurisdictional levels. We want all stakeholders to engage in standards development either directly or through appointed/elected representation.

Two Public Health Foundation Board members were asked to comment on the concept of a Web-based resource for health data standards information
The Commissioner of Health for Lexington - Fayette County Health Department, Kentucky, John Poundstone, MD, MPH suggested "…a clear and easily digested format is a worthy goal." In addition he stated that "TrainingFinder.org is an excellent resource for trainers (as well as for people who are seeking information about courses)."

The WRC would benefit by identifying training opportunities on its site via TrainingFinder.org and may be able to gain some insight into the advancing field of distance-based education thereon.

Fredia S. Wadley MD, MSHPA, Commissioner of Health,
Tennessee Department of Health, also lent some words of wisdom to the WRC efforts with additional consultation from Richard C. Urbano, PhD, Assistant Commissioner, Bureau of Health Informatics, Tennessee Department of Health.

"We look forward to having concise and authoritative information on HIPAA as it relates to individuals working in public health.

As I am sure you are aware, the amount of material available on HIPAA is overwhelming. Every day I receive brochures offering training on HIPAA, articles in trade and professional publications setting out what will and what will not happen as a result of HIPAA. This is in addition to coverage in the media. We are also inundated with list server postings, Webcasts, teleconferences and emails on various aspects of HIPAA. We are drowning in data when we need is information.

While much of what is available is important and relevant and may at some time be useful, it is too much, disorganized and not focused. What we need are materials that are Structured, Focused and Targeted.

By structured, I mean a hierarchical set of topics or learning modules that go from broad to specific allowing the learner to easily navigate from an overview to detailed materials easily. It should be possible for the learner to easily skip over material that is already known. By focused, I mean that the modules are broken up into small coherent units. If we are going to keep learners' attention and not make the task burdensome, they need to be able to incorporate the learning experience into their workday. Modules should take from 15 to 30 minutes to complete. The learner should understand the objective of the module from its title or a short description. Of course, the learner should have the opportunity to test their knowledge and understanding in a non-threatening way. By targeted, I mean that the material needs to be specifically relevant to public health. Much of the material available now is not targeted to public health and it is often difficult to see how it relates. This is particularly difficult because public health may well be a "covered entity" in some aspects of what we do and not in other aspects. Materials, which do not make a clear distinction in the role of public health being addressed contribute to misunderstanding and confusion. The questions I hear most often is "I am a <fill in the blank> in the Health Department. How does HIPAA affect me with our <fill in the blank>?"

Within the next few months, all county and metropolitan health departments in Tennessee will have high speed Internet access and thus will have full access interactive multi-media materials."

When the WRC WG gets it straight from public health leaders, practitioners and researchers via surveys or through direct contributions as above, our mission becomes 'crystal' and our design strategies enhanced. Continued suggestions, feedback and constructive critiques of WRC WG plans will help in the design a 'world-class' consensus-based resource!

WEB-SITE DEVELOPMENT

Unique Web Entity
Although the WRC currently resides as part of the over-all Consortium pages at the National Center For Health Statistics (NCHS) Web-site, the plan is for obtaining the rights to a preferred domain name "phdatastandards.info" and using this Web address to connect visitors to initial offerings (yet still within the NCHS site on the CDC server). Once funding is in place and technological essentials resolved, a move is planned to a new site at a PHDSC member organization (with oversight) or to a stand-alone site managed as a new legal entity.

Annotated Web-sites
The members of the WRC WG, through a series of monthly conference calls, shared e-mail messages, and some small group meetings, has managed to develop a list of annotated Web-sites, focusing on categories and Web-based content that they believe will be useful for visitors to learn about HIPAA and other HIPAA related and unrelated health data standards issues. This list of sites was based on one of three category style breakouts that the WRC WG developed as different ways of approaching health data standards information. Within this first of three sets of categories two sections were created; HIPAA and HIPAA Plus (related to HIPAA and public health data standards). Following the category headings within these two sections Web-sites with information pertinent to the category were listed. Visit www.cdc.gov/nchs/otheract/phdsc/wbasedwg_sites.htm to view the information on-line (also see Appendices). Visit www.cdc.gov/nchs/otheract/phdsc/phdsc.htm for other Consortium information. The Work Group has not yet fleshed out information for the other two category styles. However, they want to use these other complimentary systems for ways to break out the information at the WRC and as a logical system for searching and general navigation.

Developing Content
There will be substantial work in developing the additional content. One method may be to send out a survey to specific individuals on the Steering Committee or to other noted experts or agencies pertinent to the topic(s) in question. It is the mission of some agencies and organizations to provide information on specific topics. Such agencies and organizations could be asked to provide information that could be further prepared for ease of understanding within fact sheets, tutorials, etc. The projects being worked on in the Consortium will also help determine content.

Different content categorization styles could be used in a search system in the near term with adequate funding. The larger issue will be content development and the subsequent categorization of the content, but current plans call for a scalable site that grows as resources and interest grows. A web development firm can create a work-flow system that can be accessed via the Web. However, the more layers of sorting criteria that are desired for the overall site, the more work that has to be done to prepare the documents to be posted. A drop-down window that allows the assigning of documents and tools to pre-defined categories and roles can be developed and speed-up the categorization assignment as well as aid in tagging the documents/tools with dates, authors, etc.

Site Review
While building the site, web developers can put draft layouts on the Web and the WRC WG and WRC contracted staff could review it and share their thoughts. There should be a point person to finalize on issues, especially since there can

be significant style/taste differences. A system to monitor and make adjustments as external pages change their URLs or are no longer accessible would be also be helpful.

Second-Generation
As the WRC matures we envision a second-generation site with personal customization as the key benefit. If people returning regularly for research, this feature can help them zero in on information of interest. The visitor should go to the main site's home page first, where they can see important news, and added features or content at the site, then log into a secure environment with user name/password to reach their chosen "personal home page." Within this generation, advanced methods of stakeholder interaction could be built such as: audio/visual multiple participant chat, advance site query and submission systems that harness the advancing field of knowledge management, and online collaboration tools (e.g., enabling multi-stakeholder creation of documents in "real-time").

WEB-SITE MANAGEMENT

Governance
A governing Board should be easier to assemble with the knowledge that there will be minimal impact on their "day jobs" with a functioning capable staff. The WRC WG suggests a Board comprised of representatives from five to ten of the PHDSC Steering Committee member organizations. The legal entity that the Board would govern, the individual Board member responsibilities and terms, and the appointment process is still under discussion.

Staffing
Substantial funding is essential before serious progress can occur. The WRC WG envisions such funding would be necessary to arrange for contracted staff with informatics training, public health standards development experience (at various jurisdictional levels), instructional systems development skills (primarily utilizing Web-based technologies), and strong business development and managerial skills. It is expected that one staff member would suffice at the beginning to work with the Consortium's Business Development Work Group in detailing and advocating for the essential staff. Dedicated staff members are seen as needed especially in the first year or so of site development, with a part-time staff maintaining the site thereafter. First impressions matter and early/strong momentum defines winning sites. In addition, the data needs obviated by recent terrorism events call for swift and sober action. Enhanced data standards and data standards awareness will improve the efficacy of "early warning systems." Finally, HIPAA is right around the corner.

Site Promotion
Suggestions for promotion include: listservs, direct mail (including development of a regular contact database to advise stakeholders of new content or features), newsletters, journal articles, speaking at events, a compendium of PHDSC meeting proceedings, and assistance from Consortium members in marketing the WRC on their Web-sites.

Site Evaluation
In an effort to refine the site, and in addition to ongoing evaluation and an "online suggestion box," site statistics could be analyzed to determine favored tools and content, with special attention paid in the future to these areas.

Final Plans
The WRC will continue to accept feedback on this paper and through continued iterations develop a final plan.

1. Public Health Data Standards Consortium (PHDSC). (2001). Public Health Data Standards Consortium Education Strategy. [On-line]: http://www.cdc.gov/nchs/data/phdsc/educstrat.pdf

Building the PHDSC Web-based Resource Center

Appendices